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## Empowerment of Disability Benefit Claimants prior to their Disability Assessment

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## Summary

In daily insurance medicine practice, disability benefit claimants undergo medical disability assessments, performed by insurance physicians. For a large part, these assessments determine if a claimant will receive a disability benefit, and what the amount of this benefit will be. The patient-physician relationship is complicated by several issues in this specific context, sometimes resulting in dissatisfaction and feelings of injustice among claimants, which expresses itself into claimants filing complaints about physicians, and objecting to the outcome of the assessment. This thesis' main focus is to improve the insurance physician-claimant interaction by intervening on the claimant. For this purpose, the idea of patient empowerment was used. Empowerment refers to a process by which people gain control over affairs that matter to them. Through the interactive web-based intervention [www.wiagesprek.nl](http://www.wiagesprek.nl) we tried to empower disability claimants, prior to disability assessments. The effectiveness of [www.wiagesprek.nl](http://www.wiagesprek.nl) was evaluated in this thesis.

First, in **Chapter 2**, we tried to answer the question: are web-based interventions generally effective in increasing patient empowerment? In order to answer this question we performed a systematic review. Fourteen RCT studies were included, which were heterogenic with regard to included patients, types of interventions, follow-up period, and measured outcomes. After statically pooling on included outcome measure, it was found that, in comparison with usual care or no care, web-based interventions had a significant positive effect on empowerment measured with the Diabetes Empowerment Scale, on self-efficacy measured with disease-specific self-efficacy scales, and on mastery measured with the Pearlin Mastery Scale. No effects were found for self-efficacy measured with general self-efficacy scales or for self-esteem measured with the Rosenberg Self-Esteem Scale. Because of the low quality of evidence we found, however, these results should be interpreted with caution. The clinical relevance of the positive findings can be questioned as well, because the significant effects we found were, in general, small.

As in Chapter 2 it was revealed that not many studies measure empowerment explicitly (an exception was the Diabetes Empowerment Scale), **Chapter 3** describes the development of a new instrument to measure empowerment. This 'VrijBaan' questionnaire measures empowerment among people with a long-term work disability. First, a six-dimension (competence, self-determination, meaning, impact, positive identity and group orientation) empowerment model was chosen as a theoretical framework. A literature search was then conducted to find instruments that already were being used to measure one or more of these constructs. Validated and applicable instruments from this search were consequently used in a preliminary questionnaire. Then, a pilot test was conducted consulting the target population and experts, and a concept questionnaire was conducted. In a field test, this questionnaire was sent to 976 subjects who followed a vocational rehabilitation course in the years 2001-2003. Item-total correlations and factor analyses were performed on the collected data to reduce the number of items. Factor analysis was performed, and internal consistency was determined to get insight into the psychometric properties of the final questionnaire. Item reduction by item-total correlations and factor analysis resulted in a final questionnaire consisting of 62 items divided over the six subscales. Internal consistency of the subscales was found to be good. Despite this positive result, further psychometric work is needed to gain insight into the validity of this questionnaire and to further improve it.

**Chapter 4** describes the development of [www.wiagesprek.nl](http://www.wiagesprek.nl) and how its effectiveness was evaluated. To develop [www.wiagesprek.nl](http://www.wiagesprek.nl), the so-called Intervention Mapping (IM) protocol was used as a supportive tool. A needs assessment was carried out among the target population and relevant stakeholders. Semi-structured interviews were held with insurance physicians, labour experts and patient organizations, and a survey was conducted among disability claimants. With the information obtained from these initiatives and on basis of literature, an initial idea for the intervention was developed and program objectives were formulated. Initial ideas were tested in several focus groups, with claimants and insurance physicians separately. A beta version

of [www.wiagesprek.nl](http://www.wiagesprek.nl) was available in September 2008, which was pilot tested. After this pilot test, in which users' feedback was collected, the intervention was improved. The final version of [www.wiagesprek.nl](http://www.wiagesprek.nl) consisted of: 1) five interactive modules in which claimants are prepared step-by-step for their disability assessment (estimated walk-through time 120-150 minutes), 2) general information about Dutch social security arrangements and disability assessment procedures, and 3) a forum in which experiences between claimants could be exchanged. From January 2009 until February 2010 a randomized controlled trial (RCT) was conducted to evaluate the effectiveness of the intervention. Primary outcome was empowerment, measured with the 'VrijBaan' questionnaire, a context-specific empowerment scale, general self-efficacy, and mastery. Secondary outcomes included knowledge, coping, active participation, claimant- and physician satisfaction, and claimants perceived justice. Additionally, a process evaluation was conducted alongside the RCT.

In **Chapter 5**, this process evaluation revealed the following: first, the interventions reach was low. From the 2780 approached disability claimants, only 242 (9%) participated in the trial. Although no information was available on most non-participants, reasons for non-participation that were most mentioned were: not having access to the Internet or an email address, and not willing to fill out questionnaires that were part of the trial. Once participating, claimants not always used the intervention as intended: surprisingly, 33% never logged on to the website after enrolment. On the other hand, 32% used the intervention for more than 2 hours. Reasons for non-compliance were: a lack of time to use the website before the assessment and a lack of need to extensively prepare for the assessment. As compliance was ambiguous, claimants that actually used the intervention were satisfied. Also, they perceived the intervention to be effective in order to gain knowledge about disability legislation and procedures, in gaining right expectations towards the assessment, and in order to communicate effectively with their physician. In the process evaluation claimants gave suggestions for improving [www.wiagesprek.nl](http://www.wiagesprek.nl). Altogether, the conducted process evaluation gives implications to improve aspects in the implementation strategy of the intervention and to the intervention itself. These improvements are imperative to enhance the interventions uptake in the future.

**Chapter 6**, the most important chapter of this thesis, describes the effectiveness of [www.wiagesprek.nl](http://www.wiagesprek.nl). In the RCT, claimants were randomly assigned to an intervention group (n=123) or a control group (n=119). Participants who were randomized into the intervention group were able to logon to the website [www.wiagesprek.nl](http://www.wiagesprek.nl). Participants from the control group were directed to a 'sham' website with commonly available information only. Outcomes were assessed at baseline, 2 days before the disability assessment, as well as 1 day, 6 weeks, and 4 months after the disability assessment. Results from the RCT indicated that the intervention had no significant short- and long-term effects on empowerment, but the intervention increased claimants' knowledge significantly compared to the control group. Claimant satisfaction with the disability assessment interview and claimant perceived justice on the outcome of the assessment were lower in the intervention group (statistically not significant). Furthermore, the intervention had a significant negative effect on claimants perceived procedural justice.

As compliance with the intervention was low, it was interesting to find out whether, under the condition that is being used, [www.wiagesprek.nl](http://www.wiagesprek.nl) was effective. To examine this interventions' so-called 'efficacy', **Chapter 7** describes conducted subgroup (per-protocol) analysis. To estimate efficacy, several sub-groups were analyzed on basis of different compliance measures. Dose-response relationships were investigated by using total time registration data. Predictors of compliance were additionally determined using a stepwise backward linear regression technique. On basis of the per-protocol analysis it was found that the intervention did not have a significant positive effect on empowerment. However, knowledge, general self-efficacy, coping and active participation were significantly higher among high-compliant subgroups, compared to controls. The intervention had an adverse effect on claimants' perceived procedural justice. Dose-response relationships were found for context-specific empowerment, knowledge, coping and claimants' active participation. Being born in the Netherlands and feeling helpless towards the disability assessment predicted high compliance.

In the **General Discussion** the results from this thesis are summarized. The overall conclusion is that [www.wiagesprek.nl](http://www.wiagesprek.nl) cannot be considered an effective empowerment tool, but it can serve as an effective information source for disability claimants in the Netherlands. The most important reason for a lack of effect on empowerment is the high rate of participant non-use and non participation. Furthermore, it seems that by focusing solely on claimants in the complex context of the claimant-insurance physician interaction, expected benefits can not be reached. Practice implications are given to possibly improve effectiveness in the future.

## Samenvatting

Dit proefschrift beschrijft een onderzoek dat zich afspeelt binnen de verzekeringsgeneeskunde. Een belangrijk onderdeel van de verzekeringsgeneeskunde is de beoordeling van arbeidsongeschiktheid bij mensen die bijna 2 jaar verzuimen van hun werk. In Nederland gebeurt dit in het kader van de Wet Werk en Inkomen naar Arbeidsvermogen (WIA). Tijdens een arbeidsongeschiktheidsbeoordeling wordt bepaald óf een cliënt een arbeidsongeschiktheidsuitkering ontvangt en hoe hoog deze uitkering wordt. Een belangrijk aspect van de beoordeling is het gesprek dat een cliënt heeft met een verzekeringsarts. In dit WIA-gesprek bekijkt de arts of de cliënt op medische gronden in staat is om te werken. In de praktijk leveren deze gesprekken veel discussie op. Regelmatig voelen cliënten zich onrechtvaardig behandeld en zijn ze ontevreden over het gesprek met de arts. Daardoor dienen cliënten klachten in over de arts en tekenen cliënten bezwaar aan tegen de uitslag van de beoordeling.

In een poging deze problemen te voorkomen is de website [www.wiagesprek.nl](http://www.wiagesprek.nl) ontwikkeld. Het doel van deze interventie is het verbeteren van de cliënt-verzekeringsarts interactie door cliënt empowerment. Empowerment is een proces waarbij een individu controle ervaart over een situatie die voor hem of haar belangrijk is. De centrale vraag in dit proefschrift is of de interventie [www.wiagesprek.nl](http://www.wiagesprek.nl) als een effectief middel kan worden ingezet in de verzekeringsgeneeskunde.

In **Hoofdstuk 2** van dit proefschrift is allereerst een literatuuronderzoek gedaan waarin gekeken is of interventies via het internet in het algemeen in staat zijn om empowerment bij patiënten te verhogen. Uit een literatuuronderzoek zijn daarom 14 gerandomiseerde gecontroleerde onderzoeken (RCTs) met elkaar vergeleken. Veel verschillen zijn er tussen deze RCTs te vinden met betrekking tot de onderzochte patiëntengroepen, type interventie, timing van de metingen en de gemeten uitkomstmaat. Nadat per gemeten (empowerment gerelateerde) uitkomstmaat de onderzoeken zijn samengevoegd in een meta-analyse kwamen de volgende resultaten naar boven: online interventies hebben over het algemeen een significant positief effect op empowerment (gemeten met de Diabetes Empowerment Schaal), op 'self-efficacy' (gemeten met ziekte specifieke instrumenten) en op 'mastery' (gemeten met de Pearlin Mastery Schaal). Geen effecten werden gevonden op 'self-efficacy' (gemeten met algemene instrumenten) en zelfvertrouwen. Door een gebrek aan bewijskracht moeten deze resultaten echter voorzichtig geïnterpreteerd worden. Verder kunnen vraagtekens gezet worden bij de klinische relevantie, aangezien de positieve effecten vaak klein waren.

In **Hoofdstuk 3** is de ontwikkeling beschreven van een nieuw empowerment meetinstrument dat is ontwikkeld door het REA-college Nederland. Deze VrijBaan Empowerment vragenlijst meet empowerment bij langdurig arbeidsongeschikten. Bij de ontwikkeling van dit meetinstrument is uitgegaan van een theorie die stelt dat empowerment uit 6 dimensies bestaat, te weten: competentie, zelfbeschikking, betekenis, impact, positieve identiteit en groepsoriëntatie. Een literatuuronderzoek is uitgevoerd om bestaande instrumenten te vinden die reeds één van deze dimensies beogen te meten. Gevalideerde en toepasbare instrumenten zijn geselecteerd en samengevoegd in een eerste conceptversie. Vervolgens is een pilot uitgevoerd met de doelgroep en deskundigen om overbodige vragen uit deze versie te schrappen en nieuwe toe te voegen. Hierna is de vragenlijst verstuurd naar 976 cliënten van een revalidatiecentrum. Item-totaal correlaties en factor analyses zijn uitgevoerd op de verzamelde gegevens om het aantal items te verminderen. Resultaat is een definitieve vragenlijst, bestaande uit 62 vragen verdeeld over 6 subschalen. De interne consistentie van de subschalen is goed gebleken. Ondanks dit positieve resultaat zijn verdere inspanningen nodig om een beter inzicht te krijgen in de validiteit van de VrijBaan vragenlijst.

**Hoofdstuk 4** beschrijft de ontwikkeling van de online interventie [www.wiagesprek.nl](http://www.wiagesprek.nl) en hoe deze op effectiviteit is geëvalueerd. In de ontwikkeling van [www.wiagesprek.nl](http://www.wiagesprek.nl) is het zogenaamde 'Intervention Mapping' protocol gebruikt. Eerst is een uitgebreide behoeftepeiling gedaan onder de doelgroep en betrokken partijen. Semigestructureerde interviews zijn gehouden met verzekeringsartsen, arbeidsdeskundigen en